

**STATE COUNCIL FOR PERSONS WITH DISABILITIES'
HOME & COMMUNITY BASED SERVICES WORKGROUP**

August 14, 2017 – 1:30 PM

Smyrna Rest Area Conference Room, Smyrna

PRESENT

Terri Hancharick, Co-Chair; Jamie Wolfe, Co-Chair; Eddi Ashby, DDDS; Anthony Carter, JEVS; Kim DeShields, Easter Seals; Jody Hougentogler, BIAD/Advocate; Pat Maichle, DDC; Tammy McCabe, DMMA (for Kathleen Mahoney/Staci Marvel) via phone; Daniese McMullin-Powell, SCPD; Ann Phillips, Parent/Family Voices (via phone); John McNeal; and Jo Singles, Support Staff.

Guests: Dava Newnam, DSAAPD
Cindy Mercer, DSAAPD
Mary Chaisson

CALL TO ORDER

Terri called the meeting was called to order at 1:40 pm. Everyone introduced themselves.

ADDITIONS/DELETIONS TO THE AGENDA

- PAS – New Ways Regarding Program Utilization with United Health Care
- Defining Mission
- Community First Choice Option
- DDDS Paying for Support Staff for Clients in the Hospital

APPROVAL OF THE MINUTES

Terri made a motion to approve the minutes from the June 7th meeting. Ann seconded the motion and minutes were approved as submitted.

BUSINESS

Issues Affecting Families with Children and Remaining in the Community

Ann spoke about obstacles affecting families and movement on a waiver or legislation about medically complex children. Issues that she hears about affecting families on a regular basis are:

- Lack of nursing and its effect on families' jobs, having to take off at a moment's notice.
- It seems that families with more complex medical issues were receiving more denials and having to fight for things.
- Families with children dealing with lack of medical supplies and DME (Durable Medical Equipment) providers is reaching a new level of availability. The lack of service of the available DME providers needs to be checked out. There should be choice with DME providers

and there is not. The lack of quality of medical supplies, for example, diapers for children over three, is causing other medical issues. If the MCO improved their reimbursement, they could receive quality diapers. Now they have to pay for ointment, etc. due to problems with low quality products.

- There seems to be a trend of parents receiving denials for home health aides if there are any type of behavior issues (part of disability) with a child. Also, home health staff are not trained to work with behavior issues. John asked if there has been a change in policy related to this. Tammy will take this question back to DMMA. Jamie recommended that DMMA have a representative attend meetings in person. Tammy will pass the recommendation to DMMA. Terri asked if the Lifespan Waiver could be helpful, but this would only help those aged 12 and up. Ann stated that she will be attending a Medical Care Advisory Council meeting tomorrow and hopes to get more information. Ann stated that another problem is finding day care. There are no respite hours available for children on Medicaid. Dava said that the new waiver allows for respite hours, but that it is a capped amount for those aged 12 and over. DDDS provides respite hours.

John will contact the Delaware Association of Home & Community Care to get more information. They will be invited to attend a meeting and have an open discussion with policymakers. Jamie has a contact that she will also check out. Jamie spoke about barriers with home health agencies. John spoke about others that could attend meetings, for example, Dr. Mangler (Board of Nursing), but we need a clear and concise understanding of what the group wants.

Terri stated that we need to address barriers to the community and how to rectify them. Ann commented that we were going to have people attend to get information, like the Board of Nursing and then decide on a path forward. There was discussion about policy vs. what the law states. Also, there was discussion about when the Waiver Program was administered by DSAAPD, it was well run and not as many obstacles or barriers. A list of topics for future discussion was created as follows:

1. Scope of Nurse Delegation, RE: Medication.
2. Enhanced Awareness/Education, RE: Resources Accessible through Medicaid.
3. HHA's assertion that they are not responsible for back-up.
4. Lack of Coordination of Care under Medicaid Waiver especially with dual eligibles. Consumers get transferred to lists of providers without facilitation of access.
5. Mission: Identify barriers to optimum access to HCBS and to identify and bring together stakeholders to facilitate resolution to these barriers.
6. Clear definition of PASA Agency/Attendant.
7. Lack of DME providers. "New Motion" Monopoly? Lack of Medicaid-MCO Reimbursement forcing out providers?

8. “Attendant-share” concept between HHA’s: If Attendant of Agency A calls out, and Agency A has no back-up, Agency B Attendant is called upon.

Dava spoke about the low numbers of home health aides in Delaware and the difficulty getting quality aides. One of her goals is to build that workforce and make it a viable career choice. Currently, there are 11 personal care providers. She said that more needs to be done to improve the system. Dava will get clarifying information on what PASA provides, defining what the group is, and an explanation of the services. There were many comments regarding the difficulty in getting wheelchairs fixed from Daniese, Ann, Jamie and John due to lack of providers due to low Medicaid reimbursement rates.

Overview and Discussion of Committee’s Mission and Status

This was discussed above.

Update on My Support.com Pilot

Dava distributed a handout on MySupport, which was a proposal to the State/DSAAPD to do a pilot. There were issues with providing client data to MySupport and working through IRM. The quote from the agency was \$50,000. Terri asked if DSAAPD has spoken to other states that have this service. She stated that when they contacted California, they said that they measured success by the number of people served. Dava stated that the pilot was intended for participants in PAS under DSAAPD. DSAAPD would have 112 participants. The proposal was for up to 135 participants at a cost of \$50,000. Dava stated that most of the participants’ attendants are family members. Medicaid participants would not be included in the pilot. Jamie commented that the previous DHSS Secretary had said that Medicaid participants could be included as well. Attendant recruitment was not part of the proposal included in setting up the system \$50,000 cost. The cost of the program is \$30/month per participant. Dava stated that she was willing to look into the pilot, but that currently there are no additional dollars available so a cut would have to be made from another existing program. Jamie spoke about this being a back-up up service for her because she has no family in Delaware. Dava is willing to continue the conversation, but there are major financial barriers. She added that the State is operating at a deficit. There was discussion about the vulnerabilities of the program, including availability in an emergency situation, issues like direct payment, background checks, workers’ comp, etc. Dava stated that she would bring up the concerns to the Cabinet Secretary.

John spoke of the issue of employees of home health agencies not being allowed to work as a personal attendant care provider. Many would like the opportunity to provide back-up, but face the threat of losing their job and should have that option if they want. Dava stated that while funding is not currently available, they can continue to work on planning when money becomes available. Anthony commented that it could be valuable that people could be profiled through MySupport.com and establish beforehand an arrangement. Dava said that looking at other states would also depend on how they are set up. She sees problems with the person being employed by the participant and being called for emergency back-up. Dava spoke about the funding fluctuating from one agency to another. Dava mentioned that a cash and counseling model, but not our model, but she will check on what California is doing. It was noted that Washington, DC has the MySupport.com. She added that she did not think there would be enough participants, but that JEVS and Easter Seals were thinking about surveying their participants and attendants. Jody spoke about the lack of a back-up system and the need to look at more than one option. She spoke about hospitals dealing with this all the time and a back-up system needs to be implemented. Jamie spoke about being promised to have MySupport.com by Secretary Landgraf. Terri added that she

was hoping to have it in place. Dava said that they were asked to look into MySupport.com but money was not set aside. Jamie suggested having a sub-workgroup working on MySupport.com or similar option. Terri, a representative from DSAAPD, Jamie and Anthony will participate in this sub-workgroup. John thanked Dava for attending, but that it is vital for DSAAPD to be represented at all meetings in a consistent manner. He added that we will get more organized with the true commitment being shown.

Community First Action

Daniese spoke about the Disability Integration Act of 2017. Lisa Blunt Rochester is a House co-sponsor. The Disability Integration Act is intended for persons requiring long term care services. It gives people a civil right to live in the community instead of going into an institution. Daniese reviewed some specifics. Tom Carper has been in touch with getting in contact with the Governors regarding the Affordable Care Act (ACA), including making improvements and keeping it in place. Money Follows the Person Program is sunseting. Daniese is putting a fact sheet together for the new DHSS Secretary.

PAS – New Ways United Health Care

This was tabled for another meeting.

DDDS Paying for Support Staff for Clients in the Hospital

This was tabled for another meeting.

ANNOUNCEMENTS

None

ADJOURNMENT

The meeting adjourned at 3:32 pm. The sub-workgroup will meet on September 11th. The full Committee will meet on October 9th at Smyrna Rest Area.

Respectively submitted,

Jo Singles
Administrative Specialist

S: hcbs/notes/6-7-17